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Mini Review

Care Triad for Diabetes in Children and Adolescents - Diabetes Education, Counselling and Support

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Abstract

Around the world, there is an increase in children living with chronic diseases which includes type 1 diabetes. Care of any chronic disease not only requires medical treatment but also information, education, counselling, and holistic support. Diabetes in children is no different and child with type 1 diabetes not only requires medical management which includes insulin, diet, exercise and monitoring but also educational and behavioural interventions. Coping skills for this lifelong disorder requires diabetes self-management education appropriate to age and environment, empathy, insight, counselling and supporting relationships.

Keywords: *Diabetes; Children; Adolescents*

Introduction

Insulin-dependent type 1 diabetes is one of the most common chronic long-term endocrine disorders found in children and adolescents worldwide. Children with type 1 diabetes need to depend on regular insulin injections multiple times in a day and on adhering to many self-care tasks and life style changes to achieve optimal glycaemic control.

Challenges for children with diabetes

Children and adolescents with diabetes face significant burdens on quality of life and health. Taking insulin and other medication, checking blood glucose levels, balancing activity and food choices adds to already demanding challenges of physical and emotional growth. The complicated treatment regimen which is affected by small day to day variations in a day affects the mind, body and spirit of the child. The need of children with diabetes change as they grow and develop.

Most paediatric diabetes management is family delivered. In most of the families it a very new thing and usually comes as a very big shock for the family. Families need help to cope with the condition, while learning about diabetes and its management. Coping skills and strategy of family affects the child.

Much like the communicable diseases of the past, diabetes in children is today a stigmatized issue that is very much in the closets of many Indian households. Lack of medical insurance and government policies makes diabetes in children and youth, a big economic liability. This along with lack of education, counselling and support increase the challenges faced by children and youth with diabetes in India.

Diabetes education, counselling and support

Diabetes education

Education is the keystone of diabetes care and structured self-management education is the key to a successful outcome [1]. Diabetes education is defined as "The process of providing the person with the knowledge and skills needed to perform diabetes self-care, manage crises and to make lifestyle changes to successfully manage the disease" [2]. It begins with teaching of survival skills and continues with higher learning to fit diabetes into lives of people with diabetes rather than changing the lives to manage diabetes.

Logical Reality	Expected Ideal Reality	Evidence based suggestions
Number of people who need education are much bigger than who can give education	Diabetes education which is essential for children and their parents from the time of diagnosis, needs to be given on a continuous basis.	Every child with diabetes essentially needs to be educated on 4 key pillars of diabetes management - Insulin, monitoring, diet and exercise
Best education is useless if the learner does not understand and make use of the learning	Diabetes education needs to be tailor-made as per the understanding of the individual and the changing needs as they grow through the different stages of life [3].	Education on managing diabetes in various day to day situations of life like at school, while traveling, when there is acute illness, etc., is very important.
Lack of understanding can be due to many reasons: • Shock • Self-pity • Illiteracy • Wrong influence by society • Lack of needed connect between Health Care Professional (HCP) and patient	Diabetes education needs to be, culturally sensitive and at a pace to suit individual needs.	Knowledge on managing diabetes is essential for improving short and long term clinical outcomes and quality of life [4]

Changing diabetes in children (CDiC) program

In an attempt to address the critical gap in the management of Diabetes in India, Novo Nordisk Education Foundation, in collaboration with the International Society for Paediatric and Adolescent Diabetes (ISPAD) had launched Changing Diabetes in Children (CDiC) programme with the objective of giving children below the poverty line access to comprehensive diabetes care and management.

Diabetes Education is made to be an integral part of the programme, to improve quality of life and have better outcome in multiple ways:

1. A diabetes education curriculum comprising all the needed topics has been made for children to learn about diabetes and its management.

Self-injection techniques	Hypoglycaemia and Hyperglycaemia
Site and time of taking insulin	Diet and Exercise
Monitoring blood sugar levels/ ketones and required action	Alternative medicines-harmful effects and benefits
Actions of various types of insulins	Traveling and diabetes
Sick day rules	Festivals and diabetes
Motivation on living healthy	Exams and diabetes

Diabetes educators are supported with presentations on the above topics. These topics are discussed on multiple occasions like one to one, during camps and through educational leaflets.

2. Many useful inputs and ICE materials for educating and making these children self-reliant have been made. They have been made after lots of research, so that children can learn and enjoy both at same time. Given below is the list of few educative children materials:

Education tool	Brief description
Novo Nordisk Teaches to Take Insulin (NOTTI)	A soft toy which demonstrates insulin sites selection and helps in learning self-injection.
Make your own plate	This educational material is made on physical demonstration of a plate containing balance diet and exchange of various food items within each category.
HbA1C wheel and chart	It is educative monitor which helps in understanding average blood glucose levels from HbA1c value and thus diabetes control for people with diabetes and healthcare professionals.
MISHTI	Mishti means "sweet", it is series of story books and video of a little girl with type 1 diabetes. It touches multiple aspects of living with type 1 diabetes like, basics of diabetes management, attending a party, while travelling and sick day rules.
Snakes and Ladders	It's a board game to understand both good and bad habits for healthy life with and without diabetes.
Know about carbohydrates	It is a leaflet prepared to give understanding about simple and complex carbohydrates, reading nutrition labels and basic carb counting.

Diabetes counselling

The diagnosis of diabetes in children usually has a major psychological impact. Adjustment of the individual and family to this blow is gradual yet critical process. This process is actually path defining for the future of the child. It would be great, if every child and the family accepts the diagnosis and adopts positive adjustment for lifestyle changes and treatment plan. This is not possible and so the role of counselling comes. Counselling techniques are the therapeutic alliance between patient and HCP in which the patient's problems are understood in terms of experiences, emotions, and behaviours. There is therefore a need for training the diabetes team not only in the principles of teaching and structured education but also in behavioural change management including counselling techniques [3] for better outcomes.

Logical Reality	Expected Ideal Reality	Evidence based suggestions
Counselling techniques are widely used knowing or unknowingly to reduce psychological distress and improve compliance to treatment protocol by various HCPs.	Just as people are different and they face different challenges; the counselling approach need to change and should be evaluated at each visit and modified as needed.	Children and adolescents with diabetes have significant risks for psychological problems [6], including depression, anxiety, eating disorders and externalizing disorders. Psychological well – being, needs to be monitored for all out door patients with diabetes [7].
HCPs usually use techniques which they are familiar with, rather than technique which is apt for that individual and there is scarcity of trained counsellors who can work with these children on continuous basis	There needs to be counselling therapy for each stage after diagnosis which includes denial, anger, sadness, frustration and bargaining [8]. As the child grows into adolescent and then a young adult, counselling needs to be done for various aspects of life with diabetes and other aspects.	Counselling in diabetes requires a behavioural medicine approach [9], which involves close collaboration between psychologists, diabetologists and other health care team members.
HCPs are also vulnerable to stress and empathy/compassion fatigue, due to an emotionally exhausting environment and exposure to the suffering of patients.	Counselling sessions should include the child with diabetes, parents, siblings and all other stakeholders involved in diabetes care team.	Wide range of psychotherapeutic techniques may be utilized to enhance self-care behaviours and emotional wellbeing in children with diabetes and their families. There is no one "best" education approach; however, programs incorporating behavioural and psychosocial strategies and demonstrating respect and unconditional positive approach towards individuals with diabetes show improved outcomes [10].

Trained health care professionals are required for appropriate care of children with type 1 diabetes. With the help of Centre directors of CDiC program, several training programs have been conducted for both doctors and diabetes educators. Along with other topics on management of type 1 diabetes; special emphasis is given on psychosocial aspects of living with type 1 diabetes in these workshops. Topics such as counselling parents and positive reinforcement are part of curriculum.

Along with this, it is emphasized that diabetes educators and social workers remain in touch with children who skip their appointments and are not following instructions of doctors.

Diabetes support (Peer group)

"Peer support" is defined as "support from a person who has gained experiential knowledge of a specific condition, behaviour or situation and similar characteristics as the target population". Peer support is a concept that has generated interest recently. Sharing experiences with others undergoing the same medical or behavioural- life style tasks is an effective means of gaining mastery of tasks and improving disease outcomes [11]. Among peers, those who take on the helper role gain competency in the target medical or behavioural task as much as those who are helped [12]. In fact, volunteers who help and provide support to others experience less depression, heightened self-esteem and self-efficacy [13]. It has been observed that understanding, empathy and mutual support increases when the peers are with similar life experiences and age.

Logical Reality	Expected Ideal Reality	Evidence based suggestions
Many patients face multiple barriers to effective diabetes self-management. These include lack of sufficient knowledge of diabetes or its treatment, lack of self-confidence or skills to manage diabetes well, lack of financial resources for medications and supplies and other comorbidities and physical limitations which may be different from children in different regions.	Every person requires a social support by someone who understands, is available to listen and talk through problems that they are experiencing [14].	Since the peer groups face similar problems, they may devise ingenious jugaad (A colloquial Hindi word for grassroots innovation that is an "innovative fix," sometimes of not so good quality or of unaccepted standards used for solutions that bend rules) solutions like using an earthen pot for keeping insulin, when fridge is not there.
Peer support groups improves knowledge, skills and attitudes (quality of life) of individual patients, but also contribute to mobilising and empowering patients as a group, for instance to demand better access and quality of treatment.	'Life-long conditions requiring long-term medical interventions and adherence to medication and adjustments in life'. Social support strengthens the ability of a person to face diseases and life and thus increases the quality of life.	The success of peer support appears to be due in part to the non-hierarchical, reciprocal relationship that is created through the sharing of similar life experiences [15].
Although, there is no doubt about improved quality of life for children in peer sport group, but decreased metabolic control is also seen as a negative influence of peers especially when there is no HCP who is there as a moderator for the group.	Social support is related to coping [16]. These findings are consistent in improving quality of life and psychosocial outcomes for patients with many chronic diseases	Patients, in order to become valuable peer educators and supporters, need to be qualified, adequately trained and supported.

As part of CDiC program we have conducted and coordinated for > 700 children camps across the country. It has been a wonderful to see how well these children learn what is being taught to them for managing their diabetes well in these groups. These camps are generally led by doctor or diabetes educator and have minimum 10 to 250 children with their parents at one place. The camps are meant to

provide comprehensive care, mass education and social support for the children enrolled in the program. Most of these camps consist of these three elements:

- Diabetes education
- Experience sharing
- Fun activities.

To make peer leader and interested parents better versed in scientific knowledge about diabetes, few parents and peer leaders are involved in diabetes educator workshops organized under Changing Diabetes in Children Program.

Conclusion

The time allotted for an outpatient visit is often inadequate to address all of the questions and problems that a patient has about diabetes management and self-care. Evidence suggests that children with type 1 diabetes do better when they receive effective treatment within an integrated system with self-management support and regular follow up. Evidence also suggests an organized system of care includes doctors, nurses, diabetes educators, dieticians, social worker and peer support groups. These all are essential in producing positive outcomes. Best of diabetes education fails when it is not coupled by appropriate counselling and support. Only counselling does not work till a person gets an appropriate support and diabetes education. Best of support fails when it does not works on principals of diabetes education. Changing Diabetes in Children program is trying to provide all three in resource limited settings as all three are essential for comprehensive care of child with type 1 diabetes.

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